Healthy Communities Access Program

Advocating for the Underserved: The Reality of Healthcare in the U.S. By: Gloria Wilder-Brathwaite, MD, MPH

I am moved today. I feel the power in this room. I feel the energy and I want to thank you for inviting me to be a part of something so important. The Healthy Communities Access Program, in some ways, is an experiment. It is an experiment in trust, faith and community building. The goal is to see whether a variety of very different communities can build integrated models of health care delivery. But what does that mean? What does it mean to the uninsured person on the corner? What does it mean for the family who does not have access? Today you commence on a journey and you will have many watching and analyzing the path you take. Some are sure that this experiment will be like many previous experiments of urban and rural community building. They are sure you will fail. But, the past does not predict the future. We have the power of knowing the truth that strengthening communities happens when power is shared between the community's leaders and its most fragile members. You are community leaders. Most of the people in this room are in the privileged class, including myself. We have been able to move ourselves out of poverty. We are insured or have access to healthcare. Like it or not, you are not who you report to serve. This is a difficult but important realization, for until you acknowledge your privilege; you cannot invite those in struggle to equally partner with you to improve their circumstance. If we continue to pretend that we are in poverty or that we know the needs of the currently underserved, we will end up creating a service-disconnect. We will create great programs that no one needs and that may not serve the targeted population. If we do not acknowledge that we are experts in building models, but novice at understanding the struggle, we will continue to waste millions of dollars in public and private grant funds under the guise of doing the wrong thing for the right reason. Let's hit the nail on the head. If you have not included community recipients as equal and paid partners in the development of your program, you may have already failed.

On a day when we stand in the shadows of Dr. King, a day when you sit in the capitol of the most powerful nation on earth, on this day at this time, I hope you will find in my words, the strength and courage to include those who you want to help. I hope you will leave here willing to include both the community leaders and community recipients as equals in a struggle to reform healthcare in your hometowns.

So who am I and how dare I come here today and tell you what to do? Where do I get off giving advice? I am a pediatrician who provides care out of a 38-foot mobile medical unit. This is my 12th year of climbing on board a blue steel-framed clinic and driving out to high-risk communities and giving care. I am a product of my collective experiences in Ivy League schools and on the streets of our urban cities. I was raised by a single mother. My mother had three children and an alcoholic husband. Her husband, my father, was what used to being called a bum. My father slept on the street grates of the subway we took to go shopping. He had his up and down years, some times he held a job and an apartment, while other times it was all he could do to hold onto life.

My father left us when I was three years old, after he had physically and mentally abused my mother. My mother worked three jobs a day to get us off welfare. She completed the 9th grade in school and at thirty-five she earned her GED. My mother would tell us that her goal was to take care of us, "nothing will ever happen to you as long as I am here." And we believed her and she was right. She would remind us that there were bigger problems in the world than what we were faced with and that as bad off as things were for us, there were others who had it worse. I did not believe her. For as a child, I was often sick and often hungry. Although I was always fat, I was never full. We ate what we had. We slept at night on lawn chairs in the kitchen in front of an open stove. Since we had no heat in our house, the stove was the only source of warmth. My mom would put pots of boiling water on the stove, which she would refill throughout the night. In the morning, we would wash in the kitchen sink because we had no working bathroom. I washed in the kitchen sink well into high school. I would wait to use the toilet until I got to school. I loved school.

My mother was called a welfare mom, a dead beat when I grew up. I just called her mommy. When I woke up in the morning whether it was in front of the stove or on the floor in the Cab Company where she worked, she was always there. If I had been raised today in 2003, my mother would have been reported to child protective service and I would be in foster care. Poverty is no longer socially acceptable. For single mothers in struggle, we often criminalize their inability to care for their children.

Because of the courage of my mother, my siblings and I have earned two bachelor degrees, three master's degrees, one Ph.D. and one doctor of medicine.

I loved my father with all his weakness and faults. My father died a homeless John Doe in a public hospital on the same day I gave birth to my daughter in a wonderful private hospital. I mourned my father. I remember my brother calling me as I lay in the hospital bed with my newborn baby girl. My brother said, "Daddy died." And for me a chapter in my life was forever slammed shut, because I could not save my father. All the studying, all the tests, all the years of working to become a physician did not allow me the opportunity to rescue him.

My mother was my hero because she raised her three children not to feel bad about our circumstance in life. We were not the ghetto we grew up in. She raised us to see the trees that grew in Brooklyn. She raised us to notice the flower that pushed up through the concrete. She raised us to give back, even though other people may have pitied us and may have felt the need to be charitable to the three children who slept on lawn chairs in front of the stove and who washed in the kitchen sink. My mother raised us to be grateful. Grateful that we had a stove to sleep in front of, grateful that the morning would come and we could go to school and use the bathroom, and grateful for the opportunity to rise above our circumstance and help somebody who had less than us.

I was born and raised in struggle but I made it out. I made it solidly into the middle class (the privileged class) with my four children. Now I get to

choose to live with struggle in the community that adopted me here in Washington, DC. Honestly, I am wounded by the struggle. I have seen too much. My twelve years of riding out on mobile medical units have been both a blessing and a curse. I am blessed because I know that there is a link between every person. I do not wonder about matters of religion and the meaning of life. I have been blessed to see the meaning of life in the eyes of people with only hope on their sides; people who hang on and do the right thing despite a system of social injustice that has failed them time and time again. Children who watch hours of television programs depicting a life they may never see, but who are not bitter and jealous. Children who spend their entire childhood alone in foster care battling HIV and cancer with only kind strangers to hold their hands. Children who wish for families instead of toys, children who ask for pain medication instead of candy.

On the other hand, I am cursed by an unending aching in my soul to stop the world for a minute and give us all a reality check. The need for us to provide fair access to quality healthcare to all people who are within our borders is unquestionable. This nation must lead the world in developing models of healthcare delivery that can be replicated internationally.

Martin Luther King Jr.: "The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy."

When I went to medical school, I was taught that confidentiality extended not only to the patient's story, but also to your own. We were taught not to burden the patient with your own troubles. When you walk in that room you are a sponge ready to soak up their problems and when fully saturated, ready to wring out solutions. Although it is true that medical professionals must keep some professional distance, it is wrong for us to cover our frailty in a cloak of omnipotence. It is wrong for us to pretend that the struggle our patients face is an individual struggle when we know it is a community struggle -- it is a societal struggle.

In medical school at Georgetown University, our first lecture was from an Irish Priest named Father O'Brien. In the great lecture hall, he said to us, "I hope you will all be with us in four years, but just in case some of you are not, I want you to learn the most important lesson of being a doctor right now."

"Learn the meaning of the word empathy. Know that it is much more important that you empathize with your patient than to sympathize with your patient. No one needs or wants your pity. They want to know that you hear them, that you are listening and that you respect what they have to go through." I carried Father O'Brien's lesson with me and I still do.

I learned quickly in my third and fourth year of medical school that the lesson of empathy was really about opening your heart up to care deeply about someone who will only touch your life for a short period of time.

Two weeks ago, a 20-year old who has been my patient for 11 years came to see me. I have been the pediatrician for him and his three brothers most of their lives. He and all his brothers had severe asthma. When I first meant them, they did not have insurance or a doctor. They used the emergency

rooms for their care. All the children had been admitted to the intensive care unit on numerous occasions due to the asthma that robbed them of a normal childhood. I started making home visits with them and discovered a closet full of medications, nebulizers, peak flow meters, inhalers and humidifiers. All were prescribed by different doctors from different emergency rooms throughout the area. The mother and the boys did not know how to use any of them, so whenever one of the kids was sick, they would try all of them. We threw out all the medications and gave the boys two medications. We made the oldest boy the Captain and put him in charge of his younger siblings. Within a month, they could each demonstrate the proper use of their meds and none of them has been hospitalized for their asthma since. These boys grew up to bring me poems and raps songs. They talked of hitting it big and buying me a new mobile medical unit. The Captain (the oldest) was not good in school and drifted away from it after a teacher told him that he could not graduate. His younger brother, who also dreamed of fame, began selling drugs and was incarcerated twice by the time he was 16 years old. Two weeks ago, the Captain, now 20, came to see me on the van. He told me his brother had been killed in a car accident resulting from a shootout. He told me he was not going to the funeral because he could not handle it. He had nothing to offer to his family. He couldn't help. I told him he was going because I was going to take him and that he would stand up and be a man for his younger brothers. We helped the family raise money. The community of Washington, DC donated the church, the casket, the flowers and the burial plot. No one passing the church that day knew that this funeral almost did not take place. As I entered the church, the 20-year old Captain stood in the front row holding the hand of one his brothers. His other brother sat in the back row of the church, angrily looking at the casket.

I walked to the Captain and whispered in his ear, "Today you became a man." After the service, he thanked me and asked me to help him get his GED.

The struggle of families living in poverty is a struggle that is greater than just a lack of healthcare. In some communities, it is a lack of hope. In my community, we rise to the challenge to bury our young but what are we doing to save them?

I have spent the last year traveling the country to find out for myself whether this problem is a problem of the urban areas of this country or is it a national and perhaps a global problem. Have we lost the ability to provide basic human rights to our neighbors? Have we allowed our major public systems, that should be ensuring justice and equality, to become corrupted by the mentality of survival of the fittest?

I know that the problems of the children of the District of Columbia are not urban problems. They are not black problems. They are not poor people's problems. They are all of our problems. Like it our not, we are all linked. When people inappropriately use emergency rooms because they do not have regular doctors, we all wait longer to get the care we need. When we fail to teach and practice preventive medicine, we all become exposed to diseases that once were eradicated. When we refuse to set a minimum basic standard of healthcare for our neediest citizens, then we are risking the health all our citizens.

The definition of public health across our nation has changed. Public health has come to be synonymous with two things: emergency preparedness and poor people's healthcare. For most Americans, the thought of using the public health systems of this country is frightening. Why have we, the health care providers, abandoned the pledge of "do no harm" in exchange for a pledge of "mitigated liability." Why are we so afraid of the very system we have created, that we allow our public hospitals to crumble and ignore massive failure in public health delivery? Is it ok to be a passive advocate in the current healthcare crisis?

The passive advocate is the person who toils away always wanting to change the system but failing to seize the opportunities for change because of the complications that change will bring. The passive advocate can have power in large numbers but only rarely finds enough people to go along with them to feel comfortable with change. The passive advocate is what most medical providers have become. We know the truth and we are afraid to say it. We are afraid to tell the stories of the patients who die from diseases we can treat. We are afraid to tell the truth when the media is shocked by four children in foster care who are starving. We are afraid to say that hundreds of children in this country are starving and that thousands of children in this country will begin and end their childhood in a foster care system that cannot nurture them and often cannot even keep them safe. We are afraid of our true calling as physicians to not only do no harm but to do good.

I know that it is not easy to speak up and take a stand but it is necessary. Believe me I have rolled the dice a number of times. My voice has been loud enough to awaken the sleeping giants of the healthcare industry and I have stood before powerful people who graciously reminded me where my bread was buttered. I say today, that I don't care who cuts my check and I have lived without butter before, and I will again if I have to. I am going to keep speaking out until we provide the basic human rights of food, shelter, education and healthcare to all the children of this country and all the children of the world.

Maya Angelou said, "Without courage you cannot practice any other virtue consistently."

Since 9/11, there has been a lot of effort and money put into building a homeland security department. In an attempt to make us all feel secure, we have watched our nation spend billions of dollars on airport security, securing our borders, wars overseas, purchasing iodine and small pox vaccine, each large city now has a emergency preparedness office with high technology and mobile command vehicles ready to come to the rescue and report when aliens attack.

Well, I am not impressed. How do you help the public in times of a national or local disaster when there is no public health system? The foundation of emergency preparedness is a well functioning public health system. Not a public health system dependant on donations from the private health system to survive. Let's be honest, in most regions of the country, the public health system is so broken that it cannot take care of the thousands of people who currently use services within the system. What will happen when millions of people show up on the doorsteps of the public health clinics and hospitals? What happens when private hospitals decide they have given enough charity

care and charge premium rates for premium care? This is not the future that I am describing. This is now.

In the Nation's Capitol, there is no public hospital. Our only public hospital collapsed in a sea of mismanagement and scandal two years ago. Since then, our city has struggled to restructure an aging and disjointed public health system that has no core leadership and a collection of crumbling clinics. Our city has seven private hospitals; six of them located within a few miles of each other on the wealthiest side of our city. One sole hospital sits in the area where the public hospital once was. The only private hospital on the impoverished side of the city is now in bankruptcy. The private hospitals are fighting in the newspaper to convince the public that they cannot take on more charity care. The hospitals are not being callous they are telling the truth. The private system is being drained by public need. The safety net providers who run the nonprofit free clinics are overwhelmed with requests for help from the working poor and homeless. We have a clinic where people line up at 4:00 a.m. for the opportunity to participate in a healthcare lottery. Each day, 15 slots in the city-sponsored health insurance program are made available to the people who stand in line. The line wraps around the building and the people who do not get one of the 15 lucky spots gets the opportunity to stand in line the next day. When a reporter asked the people in the line what could be done to improve their ability to get healthcare, they did not say, give me premium insurance or provide universal care. They instead asked if a police officer could patrol the line because two people had already been assaulted while waiting for care.

Health care to the uninsured of the District of Columbia is a crap shoot. We have no affordable medications to give our patients. We have some privately insured children who use services for the uninsured because vaccines are not covered by their insurance and their parents cannot afford to purchase them. We have patients who wait for 6 months to a year to see a specialist or to get needed surgery. We have a system where the only form of universal coverage is the emergency room.

The public health system is dying of a disease we can cure. Our system is dying from neglect, starvation and selfishness, but we are going to save it. Not only will we resuscitate this system, but if I've got any say in it, we're going to fatten it up!

Who am I? How dare I get up here and lecture anyone on right and wrong. I am a product of the labeling system we have in this country. My labels include mother, pediatrician, activist, advocate, child of an alcoholic, former welfare recipient, and sister of a schizophrenic. None of these individual labels describes me, but collectively within these labels you will know all about why I am standing before you today. I have no special wisdom. If I were psychic, I would be standing in line for the lottery. I have no particular beauty or poise, I often misspeak and grammatically, many errors can be found in my writing. But I write anyway, and I speak anyway because I have to. I absolutely have to speak out about what I know to be true. The truth is the healthcare system in this country has failed and the failure of this system is collapsing our economy. Our greatest enemy is not beyond our borders but within the chambers of government, in local healthcare systems, healthcare organizations and in the areas of our country were prosperity has laid its

head. We have released our responsibility to each other and I believe that we cannot claim patriotism without responsibility for the greater good.

How did we get to a point in our country where the middle class has become unstable? When did we pass the moment when having a good job ensured quality healthcare? Today in our country, employment does not ensure quality healthcare; it does not even guarantee access to any healthcare. Increasingly, employers are dropping healthcare coverage for their employees because the cost is too high. Or they are offering healthcare plans that their employees cannot afford because they require high co-pays, or excessive premium payments. Why aren't we outraged? When a worker in this country dedicates their life to fulfilling a community dream, when they pay in, vote, and do the right thing, why are we unable to guarantee that we will be their when they need us?

I was at a conference recently and a well-respected physician described a new way of seeing patients. She described a unique method of physician visits that allows the physician to spend up to ninety minutes with their patients and to be able to do in-depth education. This sounded too good to be true. She explained that some doctors are starting to offer group visits. These are sick visits or follow-up visits in which one physician sees 10 to 15 patients at the same time in one large room. The patients take turns one-by-one explaining their problem, getting examined and then the physician goes down the line and describes their treatment. All the patients can here and see the other person's interactions with the doctor. She was excited about this new method and said that it was very popular with patients because they

desperately wanted more time with their doctor and this way they got up to ninety minutes.

She described being happy with providing these group visits but then she said, "But I would not want it for myself!" Although I love and respect this particular physician, I was disappointed. What have we done? Why have we let it get so bad that we are convincing patients to give up their right to privacy in order to get appropriate time with their provider? Why would providers, good providers, give a form of care to their patients that they would not accept for themselves?

When I grew up in New York using the public clinics, I hated going to the clinic. I was not afraid of needles. I did not dislike medicine, but I hated entering the building. I had a physical reaction to entering a building that smelled bad, was crowded with sick people, and where my mother, who I loved and respected, would be treated like trash. I was a little kid but I remember times when I would not tell my mother I was sick, times when I would shake with fever under the covers so that I would not have to go to the clinic. Why? Because when we went there, I was no longer Gloria the little girl who gets good grades and has a good mother. I was strep throat. I was lined up along the wall with other sick children I did not know. I was weighed in the middle of a large room filled with my neighbors and my chubby weight was yelled out to the clerk who recorded it for the nurse. I had my rectal temperature taken as I stood with other sick children and we each dropped our pants or pulled up our skirts and leaned over a table. I experienced group visits in 1968 and although I am sure we are much more sensitive to the need for privacy of our patients today, I would warn all providers to study the history of public health in this country; otherwise we are doomed to repeat the mistakes of the past.

Instead of promoting a system where we allow our patients to accept a level of healthcare that we would not want for ourselves; instead of continuing to compromise what is right, let us fight for justice in healthcare. Let us agree to accept the same standard of healthcare delivery whether the payer is private or public. Regardless of who is paying the bill the outcome or product of healthcare should be the same.

If I am to die from my disease, let me die because we do not have the knowledge of a cure, not because I cannot afford the cure. The solution to the problem of healthcare in this nation and around the world was given to me by a teenage girl who had early signs of cervical cancer. I told her she would have to see a gynecologist so they could do a biopsy. I asked her, "So, do you know one you want to see or should I help you find one?" She said, "I want to see who you see. I want your gynecologist." This is a universal truth of healthcare, I want what you want. I want to see the President's doctor. I want to have the same coverage the congress has. I want to be equal.

I care for people that are unpopular. I care for people who do not vote. I care for some that are outcasts. I care for the homeless. I care for the substance abuser. I care for the working poor. I also care for people who will work their whole lives in search of an invisible American dream. For people who wake up every morning, get on buses, work in your hotels and clean your offices. I care for people who have never missed voting in an election and

who think the Electoral College is where you go after you finish high school. I care for people who do not lobby and who ask for no special appropriations. I care for people who believe in the system and believe it will be there for them when they get sick. We have a calling that is greater than maleficence (do harm) we are called to do good (beneficence). It is our collective responsibility to help change what we know is wrong and to help safeguard the lives of the stranger.

There is a label to public health and to those of us who provide public healthcare. Public health has come to symbolize substandard healthcare, poor people's healthcare. Why have we allowed this to happen? We have two healthcare systems in this nation. The private system that is dollar driven where you can truly buy your way into the best care in the world. Citizens using private healthcare and paying premium rates assume a higher standard of service is being delivered? The private consumer of health assumes the provider has better training, uses better medicines and will ultimately ensure quality of care. While the consumer of public services has learned to accept a default status in the healthcare market. Public services have become the services of last resort and with this denigration of the status of public healthcare has come an alienation of both the providers and recipients of services within this system. Is the perception the truth? Are the providers of public healthcare poorly trained and unqualified to work in the private market. The answer is a resounding no. If the measure of quality care is the training and dedication of the provider, then the public and private sector of healthcare delivery are equivalent. There are good and bad physicians in all markets and fields of healthcare delivery. Not everyone who cares for the poor are saints and not everyone providing high-end healthcare are villains. There are no villains except those that we create through neglect, complacency, and injustice.

In September 2002, my life changed as I watched a young man's life drain out onto the streets of Washington, DC. I was out in my mobile unit at the end of a sunny beautiful September day. School had just let out and I was finishing my last checkup when seven shots rang out. The teenage boy who I was examining said, "It's probably construction noise." I was content to believe that until people started pounding on the door of our mobile unit. They yelled, "A man's been shot." We ran outside to find a young man lying in the gutter. He was breathing and his eyes were searching. As I began to stabilize him, I counted two bullets holes to his temple and one to his jaw. I took my gloved fingers and placed them inside his mouth to hold down his tongue and let him breath. For a few moments, I heard nothing around me although the street was crowded with children and adults. I looked at him and I said, "hang on, someone loves you, hang on." As I looked up, I noticed the police putting yellow tape around me and the young man, and I noticed the children. The children had resumed playing. There was a basketball game going on. There were adults on the corner talking. There was a woman standing behind a fence not more than 3 feet away from me with her schoolage son watching us as if it were a movie. As the ambulance came and picked the young man up, I remember thinking how did we let this happen? How did we create a society so used to death and dying that the children do not grieve?

I am not a public speaker; I am a doctor, a mother, a woman and now an activist. I will not burn buildings in protest or hurt people to get my point

across. I will not lie in the street or block your traffic. I will only speak to you and hopefully speak to your heart.

I am going to tell the truth today. In this country today, 34 states have reduced Medicaid eligibility or restricted healthcare benefits. For the second consecutive year, the number of Americans living in poverty has gone up. More than 12 million children live below the federal poverty line, that number increased by 400,000 since 2001. Eight million children remain uninsured, despite increases in enrollment to public plans. That is because the percentage of children covered by private insurance in 2002 decreased. There are 54 million families in this country that have at least one uninsured person living in their household. That one person is enough to drop that family from middle class into poverty with one major illness.

Politicians cannot solve the problems of our social systems, but we can. I ask you today to join me in a movement, the movement is not local, and not national, it is international. The movement is the fulfillment of Martin Luther King's last dream. The movement gives life to Mahatma Gandhi's meditations. The movement gives voice to Mother Theresa's prayers, and the movement makes sense of Nelson Mandela's incarceration. It is a movement for a basic standard of human dignity. We must collectively decide a level of healthcare that will serve as our minimum basic standard. Some who can afford it may buy more healthcare, but they should not be able to buy better healthcare. We must collectively decide on a basic standard for housing, food, and education. We must be willing to eat from the bowl of our neighbors and to decide that poverty in all its forms is intolerable.

In closing, I would like you to pick up a pen so I can give you some details about joining our movement. We have no website, or 1-800 number, but what I want you to draw on your paper is an arrow. Draw an arrow and point its head toward you. Every time you question how our system got like this, look at the arrow. Every time you wonder who will fix it, look at the arrow. Every time your feel sorry for the poor and wonder who will be next, look at the arrow.

I thank you for inviting me and I wish you all peace and courage!